

Welcome!

*To the world you may be  
one person, but to one  
person, you may be the  
world.*

Dr. Suess

## Dementia Capable Care Curriculum

- National Alzheimer's Project Act & the National Task Group
- Introduction to Aging
- Dementia
- Cultural Considerations
- Health Advocacy
- Caregiving and Dementia
- Community Supports
- Nutrition
- Managing the stages
- Supporting Families
- Abuse and Safety
- Bridging Services
- Medications
- Communication

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3

## Adopt a Lifespan Approach

Based on the premise that what happens in childhood and young adulthood affects the quality of life in old age.

It's never too late to make a difference, but the earlier we start the larger difference we can make.

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4

## Factors Impacting Healthy Aging

**Healthy aging is impacted by the following factors:**

- Poor lifespan health practices
- Long-term consequences of early-life therapeutic interventions
  - Ex. Post polio syndrome
- Prolonged usage of medications adding to chronic conditions in older age (adverse drug reactions & polypharmacy)
  - Ex. Thorazine

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5

## Factors Impacting Healthy Aging (cont.)

- Problems with accessing health services
  - Not having medical personnel familiar with ID
  - Not tracking risk conditions
- Age-associated pathologies
  - Dementia, cardiovascular disease, etc.
- Lack of exercise
- Poor nutrition and bad eating habits
  - Ex. Chewing, swallowing problems in Cerebral Palsy

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6

## Challenges to Healthy Aging in Adults with ID

### **Medical history is often incomplete or unknown.**

- Staff turnover
- Family not available for information, historical documentation unavailable
- Health care provider turn over
- Providers not understanding baseline functioning of the presenting older adult with ID
  - IDEA: Video can provide a visual of the person over their lifespan.

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7

## Continued

### **Lack of systems for health advocacy:**

- Information provided for the appointment may not include all necessary information.
- Staff/family attending health care appointments may not be the most knowledgeable about the symptoms.

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8

## Cultural Beliefs

**Signs, symptoms, and behavioral changes may be seen as normal aging in some cultural groups.**

- Still myths about aging in some culturally diverse.
- May delay or prevent diagnosis and treatment.
- Health care providers and formal paid caregivers may also have similar beliefs based on cultural background.

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9

## 4 Most Important Facts About Dementia

1. "A loss of cognitive (thought) function **severe enough to interfere with daily functioning.**"
2. The term "dementia" describes a group of **symptoms**.
  - a. It is **not a specific disease!**
  - b. "The doctor said my son has dementia...thank goodness he doesn't have Alzheimer's!"
3. The condition we refer to as dementia may be caused by many things.
  - a. Some may be **treatable** (Ex. Dehydration, B12 deficiency)
  - b. Others are **irreversible** (Ex. Alzheimer's, Vascular, Lewy body).
4. Dementia is **NOT part of normal aging.**

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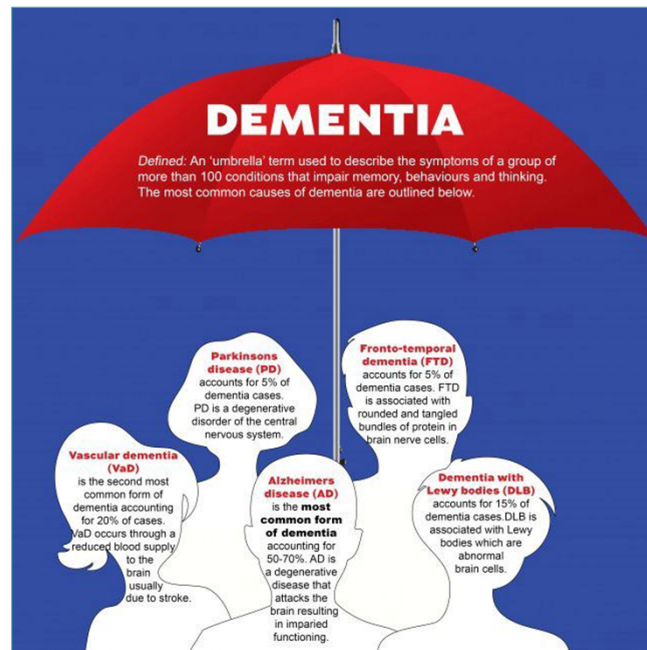
10

## Irreversible Dementias

The symptoms we call “dementia” can have many different causes.

Alzheimer’s disease is the most common.

Image: Dementia Forward

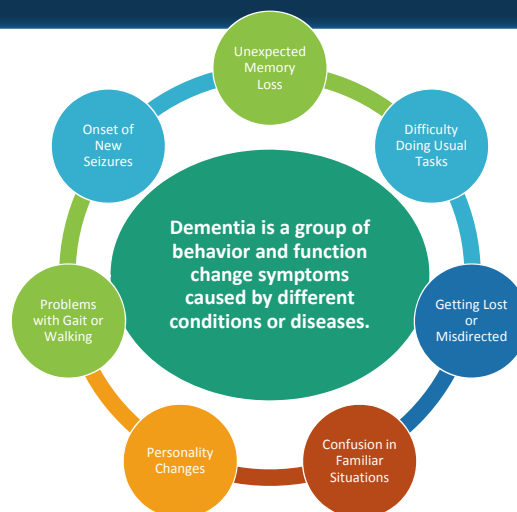


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11

## Warning Signs

*These problems must be notable and usually occur in a cluster*



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12

## Dementia Affects All Aspects of Functional Ability

Memory

Language skills

Ability to focus  
and pay  
attention

Reasoning &  
judgment

Sensory  
perception

Ability to  
sequence  
tasks

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13

## The Three D's

Dementia

Gradual over  
months to  
years

Delirium

Sudden  
onset, hours  
to days

Depression

Recent  
unexplained  
change in  
mood that  
lasts for over  
2 weeks

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14

## The Importance of Differential Diagnosis

1. Rule out treatable conditions.
2. Receive appropriate treatment and support services.
3. Maintain the highest possible quality of life and functioning.



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15

## Common Conditions to Rule Out through Differential Diagnosis

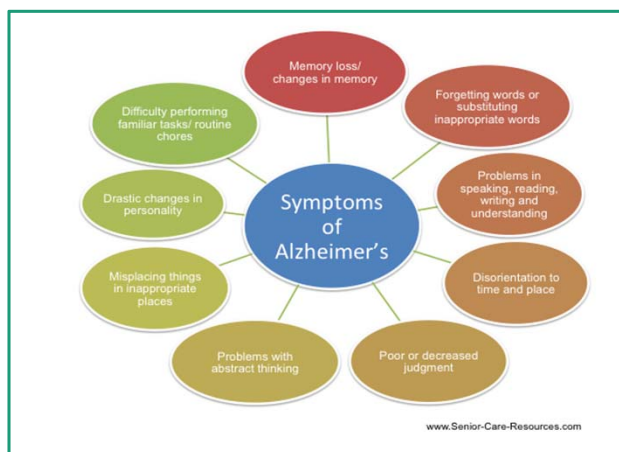
- Stroke
- Side effects of medications ★
- Nutritional deficits and imbalances
- Alcohol and drug abuse
- Hypothyroidism
- Dehydration, malnutrition
- Cardiovascular disease
- Environmental challenges
- Sensory impairments
- Depression
- Lyme disease
- Normal pressure hydrocephalus
- Sleep apnea

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16



## Differential Diagnosis of Alzheimer's Disease



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17

## 4 Steps of Health Care Advocacy

### #1. Observe

- Functional and behavioral changes observed are a form of communication.
- Use a screening tool for observation (NTG-EDSD)

### Look for changes in the person such as:

- Behavioral
- Personality
- Activity level
- Unintended weight loss or gain (10%)
- Changes in wake/sleep patterns
- Diarrhea/constipation



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18

## 4 Steps of Health Care Advocacy

### #2. Report

- Document observations
- Be accurate and specific
- Report to the right person
- Use correct forms and processes



### Important components of reporting:

- Time of the day, who is present, where did it happen?
- How often do you observe this symptom?
- What was happening before? After?
- Making sure there is a system/process for reporting to the right person!

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19

## 4 Steps of Health Care Advocacy



### #3. Prepare for the health care appointment

- Hold a team meeting (residential/family/program/individual advocates) to bring together symptoms observed.
- Prioritize symptoms and concerns to be addressed.
- Prepare a checklist or form for the attending caregiver to bring to the appointment
- Make sure the person who goes to the appointment with the individual is:
  - Included in the team meeting
  - Able to communicate symptoms
  - Has some health care advocacy skills

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20

## 4 Steps of Health Care Advocacy

### #4. Follow-up after the appointment



- Follow-up recommendations with all caregivers
- Make sure recommendations are understood.
- Are there any follow-up the questions?
- Continue observing and reporting.
- Don't give up!
  - You may have to search out a new provider
  - Be as prepared for the follow-up as for the first appointment

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21

## NTG Early Detection Screen for Dementia (EDSD)

### Demographics

### Health, Mental Health And Life Stressors

### Review of multiple Domains

### Chronic Health Conditions

- Adults with DD over age 50, DS over age 40 (and then annually)
- No special training required
- Not a diagnostic tool, but can support a clinician in making differential diagnosis

The image shows a sample of the NTG-EDSD form. It includes sections for 'Type of patient', 'Name of patient', 'Age of patient', 'Sex', and 'Race'. There are also checkboxes for 'Has each condition been checked by a health care provider?' and 'Has each condition been checked by a health care provider?'. The form is titled 'NTG-EDSD' and 'Version 1.0'.

22

## Suggestions for Modifications

Reduce visual clutter.

Organize visual clutter into specific appropriate places.

Clearly identified walking paths.

Reduce glare.

- Use matted and low gloss surfaces.
- Floors with texture and not shiny surfaces.
- No-gloss waxes and cleaning products.

## The 7 Senses, ID, and Dementia

7 senses work together to help individual function and respond “appropriately” to the environment.

Need to be able to discriminate, modulate, and integrate the senses.

Likelihood of preferred sense(s) for learning, taking in information from the environment.

Adults with ID may already have been compromised.

Dementia affects the ability to process, interpret, and respond to sensory information in the environment.

## Maximizing Location & Function

Environmental cues:

Ex. Pictures on door

Familiar textures for matching.

Ex. On the seat for meals.

Lighting.

Contrasting colors.

Reduce unnecessary stimuli.



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25

## Dementia, Environment, & Safety

Remove obstacles in pathways to prevent falls.

Create an environment supportive for the caregiver as well as the adult with ID and dementia.

Lock or disguise hazardous objects, areas.

Disguise doors for safe wandering.



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26

## Location & Movement: Suggestions

- Assume the environment is always new to the individual (remapping all the time).
- Keeping the landmarks the same as much as possible.
- Gentle touch to motivate movement.
- Modeling (imitating) to indicate appropriate behavior and movement.



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27

## Caring for Someone with Dementia Requires a Shift in Thinking.

**Rehabilitation**

**Maintaining function,  
safety, and comfort  
(Habilitation\*)**

\*Habilitation is the term used by dementia professionals to describe the non-medical interventions considered best practices in day-to-day care, in creating good environments for AD/AR patients, and within all their relationships and activities.

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28

## Support for People with Dementia and Person-Centered Approaches

IMPORTANT TO      IMPORTANT FOR



Meaning  
Purpose  
Relationships  
Satisfaction  
Comfort



Health  
Safety  
Environment  
Well-being



29  
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## Support for People with Dementia and Person-Centered Approaches



Preserve/adapt routines  
Good day/bad day



Understanding Communication



What others  
like and admire

Learning for Caregivers & Teams

Working/Not Working

Know & Do to Support

30  
TLC-PCP 2013 www.learningcommunity.us

## Bridging



- Adults with intellectual disabilities and their families affected by dementia may come in contact with following entities:
  - The state developmental disabilities authority (the 'state agency')
  - Local intellectual disability provider agencies
  - The aging network
  - Health providers
  - Social/public welfare agencies
  - Alzheimer's (or other dementia) groups
  - Volunteer organizations
- 'Bridging' is connecting diverse service networks...
  - Connecting or bridging 'silos' for a common purpose



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31

## Additional Resources

- National Task Group on Intellectual Disabilities and Dementia Practices - <http://aadmd.org/ntg>
- Early Detection Screen for Dementia - <http://aadmd.org/ntg/screening>
- Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia - <http://aadmd.org/sites/default/files/NTG-communitycareguidelines-Final.pdf>
- Consensus Recommendations for the Evaluation and Management of Dementia in Adults with Intellectual Disabilities - <http://aadmd.org/sites/default/files/NTGFinalrevisions-May16-2013.pdf>
- Guidelines for Dementia-Related Health Advocacy for Adults With Intellectual Disability and Dementia: National Task Group on Intellectual Disabilities and Dementia Practices - <http://aadmd.org/sites/default/files/Bishop-document-web.pdf>
- My Thinker's Not Working - A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports - <http://aadmd.org/ntg/thinker>
- NDSS – Aging and Down Syndrome - <http://www.ndss.org/Global/Aging%20and%20Down%20Syndrome.pdf>

32



## Want More Training?

Want additional training on the *National Task Group's Dementia Capable Care of Adults with Intellectual Disabilities and Dementia Curriculum*?

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33